



FH  
[REDACTED]

**STATE OF WISCONSIN**  
**Division of Hearings and Appeals**

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In the Matter of

[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]

DECISION

MPA/173046

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**PRELIMINARY RECITALS**

Pursuant to a petition filed March 24, 2016, under Wis. Stat. § 49.45(5), and Wis. Admin. Code § HA 3.03(1), to review a decision by the Division of Health Care Access and Accountability in regard to Medical Assistance (MA), a hearing was held on April 22, 2016, at Eau Claire, Wisconsin.

The issue for determination is whether the department correctly denied the petitioner's request for genetic testing to determine the cause of his epilepsy.

There appeared at that time and place the following persons:

**PARTIES IN INTEREST:**

Petitioner:

[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]

Petitioner's Representative:

[REDACTED]  
[REDACTED]  
[REDACTED]

Respondent:

Department of Health Services  
1 West Wilson Street, Room 651  
Madison, Wisconsin 53703

By: [REDACTED]

Division of Health Care Access and Accountability  
1 West Wilson Street, Room 272  
P.O. Box 309  
Madison, WI 53707-0309

**ADMINISTRATIVE LAW JUDGE:**

Michael D. O'Brien  
Division of Hearings and Appeals

**FINDINGS OF FACT**

1. The petitioner (CARES # [REDACTED]) is a resident of Eau Claire County.

2. On January 15, 2016, the petitioner requested genetic testing at a cost of \$5,328.50 to determine the cause of his epilepsy. The department denied the request on March 2, 2016.
3. The petitioner is an eight-year-old boy diagnosed with Down Syndrome and epilepsy.
4. Between 1 and 13% of those with Down Syndrome have epileptic seizures. This is higher than the general population. Seizures in those with Down Syndrome are more difficult to control than in the population at large.
5. The petitioner has defects in the CYP2D6 genes.
6. There is at most a 20 to 30% chance that the genetic testing will lead to clinically useful treatment.

### **DISCUSSION**

The petitioner is an eight-year-old boy diagnosed with Down Syndrome and epilepsy. Children's Hospital requests authorization to determine an origin of his seizures. The department denied her request because the test probably will not lead to a clinically useful course of treatment.

When deciding whether to approve request, the department must consider the general prior authorization criteria found at Wis. Admin. Code, § DHS 107.02(3), including whether the request is medically necessary. To be considered medically necessary, a medical assistance service must meet the following criteria:

“Medically necessary” means a medical assistance service under ch. DHS 107 that is:

- (a) Required to prevent, identify or treat a recipient's illness, injury, or disability; and
- (b) Meets the following standards:
  1. Is consistent with the recipient's symptoms or with prevention, diagnosis or treatment of the recipient's illness, injury or disability; ...
  3. Is appropriate with regard to generally accepted standards of medical practice; ...
  5. Is of proven medical value or usefulness and, consistent with s. DHS 107.035, is not experimental in nature;
  6. Is not duplicative with respect to other services being provided to the recipient;
  8. ...[I]s cost effective compared to an alternative medically necessary service which is reasonably accessible to the recipient; and ...
  9. Is the most appropriate supply or level of service that can safely and effectively be provided to the recipient.

Wis. Admin. Code, § DHS 101.03(96m).

The provider has the burden of proving that the requested service is necessary. Wis. Admin. Code, § DHS 107.02(3)(d)6.

The department's guidelines allow genetic testing when the test's results specifically allow medical providers to

develop a clinically useful approach or course of treatment or to cease unnecessary treatments or monitoring. Clinically useful tests allow providers to treat current symptoms significantly affecting a member's health or to manage the treatable progression of an established disease.

*ForwardHealth Update*, No. 2014-37. See also *Medicaid Online Provider Handbook*, Topic 16957.

The department contends out that those with Down Syndrome are more likely to have seizures and that those seizures are more likely to be difficult to control than is true of the general population. Because of this, the department contends that petitioner's seizure is "part of his established condition of Down Syndrome." According to the department, 10% or fewer of those with seizure caused by mutations will have the gene defect identified. It states that about 40%—less than half—of those with Down Syndrome who have seizures have a genetic basis for those seizures. As a result, it claims, the "vast majority of genes associated with epilepsy do not lead to a clinically useful approach or change in the course of treatment." Because the testing does not lead to a clinically useful approach or change in the course of treatment, it does not meet the guideline for approval.

The petitioner's treating physician, [REDACTED], agrees that it is more likely than not that genetic testing will not lead new treatment, but he clarified this point and added some subtlety to interpretation of the studies on this topic. He contends that given the petitioner's particular circumstances that genetic testing has about a 20 to 30% chance of identifying a genetic cause of his seizures that will lead to treatment. He concedes that this is still low but contends that the potential benefits will be great because it could lead to a drug that will control the seizures. The proper drug cannot be discovered just by trial and error because, depending on the cause of the seizures, some drugs that will help if a genetic cause is determined, will harm him if the cause is not genetic.

The petitioner's doctor has presented a strong case because he has shown that if everything goes well, genetic testing will lead to a course of treatment. But this still is only a 20% or 30% chance that it will lead to clinically useful treatment. Although this is greater than the department's estimate, it still means that a procedure that costs over \$5,000 will probably not lead to any results. Given that there is still conflict between the department and the provider's view of the likelihood of success, the petitioner has not shown by the preponderance of the currently available evidence that the requested testing is medically necessary.

The petitioner's doctor should present the latest evidence to the department and try to convince it to change its position. Genetic testing is a quickly changing field, and the department's position will evolve as new findings are made and the cost of this testing declines. Even now, nothing prevents the petitioner's provider from submitting a new request with additional information to the department. And if that request is denied, the petitioner can again appeal.

### **CONCLUSIONS OF LAW**

The department correctly denied the petitioner's requested genetic testing because he has not shown by the preponderance of the credible evidence that it is medically necessary.

**THEREFORE, it is**

**ORDERED**

The petitioner's appeal is dismissed.

### **REQUEST FOR A REHEARING**

You may request a rehearing if you think this decision is based on a serious mistake in the facts or the law or if you have found new evidence that would change the decision. Your request must be **received within 20 days after the date of this decision**. Late requests cannot be granted.

Send your request for rehearing in writing to the Division of Hearings and Appeals, 5005 University Avenue, Suite 201, Madison, WI 53705-5400 **and** to those identified in this decision as "PARTIES IN INTEREST." Your rehearing request must explain what mistake the Administrative Law Judge made and

why it is important or you must describe your new evidence and explain why you did not have it at your first hearing. If your request does not explain these things, it will be denied.

The process for requesting a rehearing may be found at Wis. Stat. § 227.49. A copy of the statutes may be found online or at your local library or courthouse.

### **APPEAL TO COURT**

You may also appeal this decision to Circuit Court in the county where you live. Appeals must be filed with the Court **and** served either personally or by certified mail on the Secretary of the Department of Health Services, 1 West Wilson Street, Room 651, Madison, Wisconsin 53703, **and** on those identified in this decision as “PARTIES IN INTEREST” **no more than 30 days after the date of this decision** or 30 days after a denial of a timely rehearing (if you request one).

The process for Circuit Court Appeals may be found at Wis. Stat. §§ 227.52 and 227.53. A copy of the statutes may be found online or at your local library or courthouse.

Given under my hand at the City of Madison,  
Wisconsin, this 27th day of May, 2016

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\sMichael D. O'Brien  
Administrative Law Judge  
Division of Hearings and Appeals



**State of Wisconsin\DIVISION OF HEARINGS AND APPEALS**

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The preceding decision was sent to the following parties on May 27, 2016.

Division of Health Care Access and Accountability